

...offering
information &
inspiration
to individuals with
disabilities and
their families
as they direct their
own supports and
services



Volume 4 Number 5
May 2006

The Heart of An Advocate

What I Learned from Ethan Ellis

by Norman Reim

"I have to admit it. When I first met Ethan Ellis, I was a little intimidated. He had an almost legendary reputation and I was already a bit in awe of him.

Ethan certainly taught me a lot about advocacy. He is "the" master of political theater. It is a delight to watch him use his intelligence, savvy and yes, his disability, to capture the attention of an individual, an audience and the cameras to make sure he gets his points across.

He also gets to the core of complex and difficult issues more quickly and comprehensively than anyone I've ever worked with. And, as anyone who has ever worked with him (or against him) can testify, he's a tough battler and shrewd negotiator.

But it's the passion and vulnerability *behind* the fighter with the legendary temper that holds the key to what I'll remember most about Ethan.

I think the most important thing I learned from working with Ethan - the thing that will stay with me the longest, both personally and professionally - came not from specific campaigns or projects we worked on, but from the sometimes rambling conversations we use to have in between.

The first few times Ethan teared up when we were just talking about "things" and he was reminiscing - through his delightful stories - about some meaningful conversation or moment he had with his father or some soul-mate friend or colleague, I knew I was seeing a side of him not everyone was privileged to see. But I also knew that without seeing that side you were only seeing part of the whole - and missing some of the best parts.

I know it wasn't the side he needed to show or have shown as he fought for the rights and dignity of people with disabilities.

"... Ethan's most
impressive trait, for me,
is not his mind
- as keen as it is -
or his strength
- which is formidable,
but his heart, which is
large, generous,
vulnerable and
imperfect.
In a word :human."

- Norman Reim
NJ Council on
Developmental Disabilities

What Makes an Advocate?

“...Our minds and our hearts, if we are true advocates, will cause us to speak out for social justice for all...”

- Frank Tetto, father

“The act of giving verbal support to a cause.”

- The Random House Dictionary

“Advocacy means speaking up for others, acting on their best interest, standing up for their rights and helping them get what they want. As far as what it takes to be a self-advocate, people with disabilities need to have an ability to speak up and be assertive. Self-advocacy requires being able to work with people on all levels and to stay strong. Advocacy is something no one can force you into. You have to love people and be willing to help them fight for their human rights...Being an advocate requires you to be a true leader by listening to people and then teaching them how to take action on their issues.”

Samuel O. Jenkins,
Self-Advocate and Northeast Coordinator
at The New Jersey Self-Advocacy

“Advocacy is making someone who is not in your situation understand what you need and why. This is not always as easy as it seems. It may take days, months or even years to accomplish...”

Charles Malvasi Jr.
Self Determination Recipient

“An advocate is a person who fights for himself or someone else to get what he needs ... An advocate can be anyone: a mother, a caring relative, friend or even a congressman or the president, but it should be someone who is knowledgeable and caring and has your best interests at heart!”

Emily Feldman
A mother, a support broker and an advocate

“I think an advocate is best described as someone who walks with someone and takes all direction from the other...”

Sue Henshaw

“An advocate is a person who listens to what another person wants and helps them achieve it. It takes a desire to help people, an ability to listen and bring people together to achieve goals, tenacity, an understanding of the resources available to assist people and a strong unwavering desire to make dreams a reality. When done correctly, there is no greater assistance any person can receive.”

Bill England
Support Broker

“People have the ability to do what they want, make choices and say what they want in their lives. As an advocate, I help people with disabilities make it happen. It gives me confidence to help other people... As a self-advocate, I like speaking up for what I want and also for others where I live and work.”

Barbara Coppens, New Jersey United Self-Advocates
Southern Region and Advocate Assistant, NJP&A

“Advocacy ... is the act of pouring your energy, your heart and spirit to give a voice to the voiceless as well as the willingness to speak out, write about and even place yourself at risk to make a better world.

In its most basic form, advocacy is about speaking out about what is needed or is unjust...True advocacy is going beyond the basics. We are all human and our needs should not be ignored because of our age, our race, our gender, our diagnosis, our place of birth or onset of injury. Our minds and our hearts, if we are true advocates, will cause us to speak out for social justice for all...”

- Frank Tetto, Father

It wasn't the side he needed to show as he almost single-handedly carried the pre-Olmstead banner against the injustice of keeping people in institutions who didn't want or need to be there; or when he was hammering home that our state and country should be ashamed that there are still such significant barriers blocking people with physical disabilities from participating in society; or as he shouted into the wilderness that economic and physical violence against people with disabilities continues to be a human outrage.

But now that he has a new son and has, reluctantly, laid down some of that burden, I think it'll be okay to publicly applaud his sensitivity and compassion.

Because Ethan's most impressive trait, for me, is not his mind—as keen as it is—or his strength—which is formidable, but his heart, which is large, generous, vulnerable and imperfect. In a word—human.

That's the Ethan I'll remember most fondly. Because that's what our work in the service of other humans should really be all about. Our shared Humanity and our individual hearts.

“Because
that's what our
work in the service
of other humans
should really be all
about.
Our shared
Humanity and
our individual
hearts.”

Even when he is at his most combative and judgmental you can always trace his motivation back to the early signals from his heart.

Whether on big stuff or small, Ethan's heart tells him what he has to do and then his head has to scramble to cover the flanks left exposed by the plunge.

It isn't always smooth but it is always true to his beliefs.

And though during our time together at the Council we may not have always seen eye to eye on the **how**, he never let me down on the **why**.

And in the end that's what matters most...

Norman Reim is the Media Director at the New Jersey Council on Developmental Disabilities. He has worked with Ethan Ellis for the last nine years. This article is edited from the comments Norman shared at the recent celebration of Ethan's retirement.

Editors Note: On January 31, 2006, Ethan Ellis retired from his work at the New Jersey Council on Developmental Disabilities, where, for the last fifteen years, he had served as its Executive Director. While there, he oversaw the Council's activities and lead the effort to support the closure of two state institutions, Johnstone Developmental Center and North Princeton Developmental Center. He worked to involve people with disabilities in public policy at every level. Under his direction, the Council helped register nearly 20,000 voters with disabilities, initiated the Monday Morning Project, a grass roots advocacy program and brought hundreds of self-advocates to Washington D.C. The Council sponsored several Statewide Disability Conventions, drawing thousands. The Council also launched initiatives to promote inclusive education for students with disabilities.

PLEASE ADD ME TO THE MAILING LIST:

Name _____

Address _____

City _____

State/Zip _____

Send to:

New Directions
CCS Communications
P.O. Box 384
Hopewell, NJ 08525

or e-mail:

consid@comcast.net

may 2006

new directions

is produced by CCS Communications under a contract for the New Jersey Council on Developmental Disabilities.

The views and opinions do not necessarily reflect those of the editor, the Division of Developmental Disabilities or the Council, its staff or its volunteer members.

Your letters and stories are welcome. Program participants and/or their families who submit published stories will be paid \$100.

Editor: Brenda Considine

CCS Communications
P.O. Box 384
Hopewell, NJ 08525

phone/fax: 609-466-0694
consid@comcast.net

Want Ads and Classifieds

Accessible Home For Sale - Wheel chair accessible home in Belvidere, NJ (Warren County). Very well maintained single level home with two bedrooms, a garage, good size kitchen, living room and two bathrooms. The home is conveniently located approximately 3 blocks from downtown Belvidere and the local grocery store.

Call Bill England 732-238-6133, or email williamsengland@aol.com

Flexible part-time position(s) available - Seeking direct support staff to work with a man with disabilities living in Bridgewater/Somerset area (Somerset County). Week night until 7-8pm to help prepare dinner and provide transportation to recreational activities and other errands. Also needed, Saturdays from 11-7pm (schedule may vary on occasion) Candidates will be working for and hired directly by this individual, but employed through Alternatives, Inc.

Call Debbie Forsythe at 908-231-9398, or e-mail dforsythe@alternativesinc.org

Writers - Share your story. Seeking individuals, family members and direct support staff working in self-directed systems (self-determination or Real Life Choices) to write about experiences and perspectives for statewide newsletter. Writers will be paid for articles and stories that are published.

Send work to Brenda Considine consid@comcast.net, or mail hard copies to PO Box 384, Hopewell, NJ 08525.

new directions

New Jersey Council on Developmental Disabilities
P.O. Box 700
Trenton, NJ 08625

FIRST CLASS U.S.
POSTAGE
PAID
Trenton, N.J. 086
PERMIT #21